

**Notes of Prostate Cancer Support Group Meeting
held at Dolphin Surgery, Haywards Heath on
Thursday 23 July 2015**

Peter Barton (Chairman) welcomed 3 new members to the meeting, and particularly the attendance of wives and partners who played such an important part in care and recovery.

By a show of hands only 3 members had undergone Radical Surgery, including himself, although 1 had undergone Radium 223 Treatment for Metastasized Cancer including the use of the newly released Chemotherapy treatment Docetaxal.

The vast majority of members were on Hormone /Radiotherapy.

Peter briefly outlined the exciting research into Immunotherapy which was showing early signs of success and may soon become the main form of treatment for many forms of cancer. The majority of cancers are caused by faulty genes and new treatments worked by stripping the cloak that surrounds these genes to allow our own immune systems to locate and repair them.

Peter referred to the use of Statins which most members were already on as it seemed that these simple and cheap drugs prolonged the time Hormone treatments worked before ultimately failing.

Finally, Peter read a paper produced by Dr Chris Parker of The Royal Marsden Hospital which gave an update of the treatment choices for Advanced Disease ([see article on page 5, Link below](#))

<http://pcaso.org/PDF/newsletters/pcaso/newslatest.pdf>

SPEAKERS

Mary Kuponiyi (Radiographer) and Patrick Arnold from Cancer Partners UK, Guildford

It was explained that Cancer Partners UK is an independent company with 8 centres - Birmingham, Elstree, Guildford, Milton Keynes, Oxford, Nottingham, Portsmouth, Southampton. These centres sit alongside or within leading private hospitals, ensuring patients can benefit from highly targeted radiotherapy as part of a completely integrated approach to their cancer treatment.

Radiotherapy

Radiotherapy is a painless procedure using radiation, usually high energy x-rays, but sometimes, electrons, and more rarely protons, to treat disease. It can cure many cancers by destroying the tumour or stopping it from growing any further.

A Linear Accelerator (LINAC) is the device most commonly used for external beam radiation treatments. It is used to treat all parts/organs of the body and delivers high-energy x-rays to the region of the patient's tumour.

Preparation of patient: CT scan - Target area outlined (tattoo) - treatment planned in 3D and checked, then compared on a daily basis.

Technical Terms

IMRT (Intensity Modulated Radiotherapy) takes approx 10-15 mins. This is a specialised way of delivering radiotherapy and is used to treat many different types of cancer. They are able to vary the strength of each radiotherapy beam to match the size, shape and position of the tumour more precisely than conventional radiotherapy.

IGRT (Image Guided Radiotherapy) allows position of internal organs surrounding tumour to be checked. These are known as organs at risk. IGRT is used to ensure accuracy during treatment.

VMAT (Volumetric Modulated Arc Therapy)

- is a faster version of IMRT (takes approx 50 seconds)
- Ensures more precision and accuracy therefore minimising exposure to surrounding healthy tissue
- ensures even dose
- fewer side effects/greater patient comfort.
- Cancer Partners UK is currently in the process of introducing VMAT into all of it's radiotherapy treatment centres.

Side Effects

These can vary from patient to patient.

Tiredness - Skin reactions - Change in bowel habits - Urinating more frequently (Cranberry juice can help with this).

Skin Care Advice

- Wash with mild or baby soap
- Do not use creams, lotions, perfumes, deodorants on the treated area
- During treatment patients should be well hydrated
- Do not change diet. Drink 1.5-2 litres of water per day before treatment starts.

Frequency of radiotherapy is assessed on an individual basis.

Clinical Trials

It was explained that the criteria for acceptance onto clinical trials can vary. Patients have to meet a specific profile. Trials are subject to very clear conditions, and patients could be chosen at random to get better results. The placebo effect can be very strong.

If anyone wishes to go onto a trial, please contact Peter Barton (Chairman)

TERRY'S TALK ON RECENT ADDITIONS TO THE SUPPORT GROUP WEBSITE

under Website headings as follows:

SUPPORT

- We are a partner support group of Prostate Cancer UK and were initially helped with set-up funds by Macmillan Cancer Support. The PC UK Helpline is manned by specialist nurses - has online community, peer counselling, brochures with news of research and treatments.
- We have recently joined the Prostate Cancer Support Federation the working name of which is "Tackle". Tackle is run by patients for patients and acts as a voice for those affected by Prostate Cancer. It also has a Helpline and provides email contact.
- Macmillan Cancer Support is a Drop-in service at Queen Victoria Hospital, East Grinstead offering counselling and information services.

The help each of these can provide is outlined on website.

USEFUL INFORMATION

Our Web-site originally provided outline information on PSA test, symptoms etc. It now includes: Notes of our Support Group Meetings, Links to videos on, for example, Keeping Fit and Healthy,

and to PCUK recent guidance to include managing bone pain, end-of-life support, sex, and prostate cancer.

We also include members' stories and experiences of particular stages in the cancer journey. More stories would be welcome and, if required, could be suitably anonymised.

NEWS

We include news of recent advances in treatment and promising research as follows:

- **Olaparib trials.** Olaparib is one of a class of drugs called PARP inhibitors. It is already licensed for use and very effective in treating ovarian cancer. It has been found that some patients with advanced, aggressive prostate cancer are having an impressive response to the drug.

- **Genetics** New light has been shone on the genetics of prostate cancer revealing it to be many diseases each driven by their own set of mutations. Many of the key mutations identified are ones that can be targeted by existing cancer drugs. We could be entering a new era of personalised cancer treatment.

- Use of Chemotherapy alongside Hormone Treatment

The findings here are potentially game-changing. Chemotherapy is one of the "last resort" treatments for advanced prostate cancer. If it is shown to have a much greater impact on survival when prescribed earlier, alongside hormone therapy, that is incredibly exciting, and we would want to see this brought forward so it can benefit men without delay.

- Big Changes in Prostate Cancer Diagnosis

A PCUK funded research project where the objective is to get the best possible shot at revolutionising how we work out a man's individual risk of developing prostate cancer, especially aggressive cancer - targeted at GP surgery diagnosis.

FUTURE INCLUSION ON OUR WEBSITE

We are currently considering including a page on the capabilities of nearby prostate cancer units: Brighton Universities and other coastal hospitals, East Surrey with Guildford, Tonbridge with Maidstone, Royal Marsden, and covering: Diagnostics, surgery, brachytherapy, external beam radiation, chemotherapy, diagnosis etc.

If anyone has any further suggestions for future inclusion on our website, we would be pleased to hear from you.

NEXT MEETING

Thursday 26 November

Dolphin Surgery Meeting Room returning to our usual 3pm - 5pm

24.7.2015